

Project Title: Hawaii Genetic Awareness, Implementation, and Data Project  
Project Number: 1 H46 MC 00188-01  
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Project Period: 06/01/01 – 05/31/04

**Problems:**

- 1) Current genetics needs assessments show that awareness of genetics among all communities (e.g. physicians, consumers, public health professionals) is low even with the advances in the Human Genome Project.
- 2) Genetics education, counseling, and referral for genetics services have not been implemented in many public health programs.
- 3) Many data systems collect and analyze the same newborn information within their own programs which is time consuming and does not provide an integrated system of data linkage.

**Goals and Objectives:**

**Goal 1:** Increase the general awareness of genetics and use of genetics resources in the state for a wide range of audiences.

- 1) Increase genetic awareness in physicians, public health professionals, consumers, legislators, and policy makers;
- 2) Incorporate genetics content and follow-up into appropriate public health programs;
- 3) Improve current genetics programs such as the Newborn Metabolic Screening Program by investigating new technologies to improve screening practices;
- 4) Help ensure that public health genetics programs have stable and sustainable funding.

**Goal 2:** Improve the integration of data systems collecting the same newborn data.

- 1) Integrate Newborn Metabolic and Hearing Screening, Children with Special Health Needs, and Early Intervention Services Program data and/or referral systems.

**Methodology:**

- 1) Educational materials and activities will be developed and implemented for a broad base of stakeholders. Materials will also be made available via the genetics program website to improve current distribution methods such as direct mailings.
- 2) Genetics content which may include education and referral for genetic counseling and evaluation will be incorporated into the newborn hearing screening program. Also, in collaboration with the chronic disease program, one model chronic disease program will be chosen to develop and implement genetics content, referral and follow-up activities

into the program. This model will be evaluated for use in other chronic disease programs.

- 3) A workgroup will investigate the practicality (validity, cost effectiveness, acceptability by the community, etc.) of adding new technology, such as Tandem Mass Spectrometry Screening, to our NBMS Program. Information from the workgroup will be presented for review by the NBMS Advisory Committee to prepare for possible program expansion.
- 4) The newborn metabolic screening program, newborn hearing screening program and birth defects program will participate in a pilot project to integrate their data systems using a common data system to reduce the redundancy of data entry and increase access to data as appropriate. This new system will have linkages to the Early Intervention Services data system to increase the referrals of eligible children.
- 5) The project staff will work to increase the knowledge and use of the State Genetics Plan to advocate for local, regional and state funding for genetics activities. The project staff will identify and publicize funding sources for genetics activities and provide technical assistance to obtain funding for other programs as time permits.

**Coordination:**

The genetics program has collaborative relationships with private agencies, health care systems, public programs, private sector service providers, and consumer groups. The project staff has also established relationships with related projects to integrate data systems and improve program collaboration.

**Evaluation:**

The evaluation will include: (1) process evaluation of the attainment of stated goals, objectives and activities within the given time frame; (2) increased integration of data and information systems related to genetics; (3) analysis of pre and post-test results from educational activities; (4) analysis of evaluation forms from activity participants; and (5) tracking the use of project materials such as the number of media segments generated, hits on the website, and requests to project staff for more information.

**Experience to Date:**

During the second year of the project we were able to: 1) Improve information on our program website to increase public awareness of genetics activities; 2) Increase genetics education for public health staff, primary care providers, teachers, students, public health students and faculty, and consumers; 4) Increase distribution our newsletter to over 1000 individuals and organizations; 5) Continue to develop and provide continuing genetics education and materials about newborn screening using tandem mass spectrometry and genetics of hearing loss; and 6) Continue to develop and implement plan to pilot software program to integrate newborn metabolic and newborn hearing screening data.

**Key Words:**

Hawaii, Genetics, State Genetics Coordinator, State Genetics Plan, Data Integration, Genetic Needs Assessment, Genetic Awareness, Newborn Metabolic Screening, Newborn Hearing Screening, Birth Defects Program, Education, Public Health